

THE DEVELOPING MIND

The Boone Fetter Clinic: Diagnostic, Clinical and Research Center for Autism and Other Neurodevelopmental and Behavioral Disorders



Welcome

It is sometimes difficult to find a trustworthy source for answers to complex questions about your child's health and development, so we provide this newsletter to bring you up-to-date information from specialists and researchers at Children's Hospital Los Angeles, a proud member of the Autism Speaks Autism Treatment Network. For more information about the Boone Fetter Clinic, or if you have a question about your child's development, please call the Autism Warm Line at 323-361-6102.

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To make an appointment, call the Autism Warm Line at 323.361.6102, email BooneFetterClinic@chla.usc.edu or visit CHLA.org/AUTISM.

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Creating a New Puberty and Adolescence Resource



By Kameena Ballard-Dawkins, member of CHLA's Autism Parent Advisory Board and co-chair of the Family Advisory Committee of the Autism Speaks Autism Treatment Network. Ballard is a leader in the autism community and recently co-authored a new toolkit for parents of adolescents with autism: the Puberty and Adolescence Resource.

Having a preteen daughter with autism left me with lots of questions about how to prepare her for puberty and the changes it entails. I worried about her ability to take care of herself during menstruation. How would I explain to her the mood and behavioral changes that often come with puberty? My self-guided research on navigating this crucial time became overwhelming. At the same time, I realized that the changes could begin any day and I knew other parents of tweens with autism who felt just as stuck as I did. We were all searching for answers.

Through my work with Autism Speaks, I was able to collaborate with a diverse team of parents, students and medical experts to develop a comprehensive puberty and adolescence toolkit. The main goal of the toolkit is to empower



parents by equipping them with practical strategies to help their children understand the changes their bodies are undergoing and how they should handle their new feelings. We used a family-centered care model, which emphasizes the role of parents and other caregivers as expert partners in their children's health care, to help guide us through the development process.

Each section of the toolkit focuses on topics that are relevant to male and female adolescents across the autism spectrum, including those who are nonverbal. A variety of scripts and visual aids are also included to help guide discussions regarding hygiene, public vs. private behavior and body changes. We also developed content that focuses on gender-specific issues, such as menstruation and wet dreams.

Once we finished developing the toolkit, occupational therapy students studying

adolescent development at the University of Southern California helped us develop a teen-friendly "voice" for the content in the toolkit—a voice that we think today's adolescents will find relatable. We also engaged parents and caregivers to ensure that the toolkit could be easily understood by a diverse audience.

After reading the finished product, I can proudly say that it has given me some great ideas. I particularly value how it helps me choose the right words to explain what puberty might look and feel like for my preteen daughter. This toolkit has really worked for my family! We're now ready to share it with the broader autism community.

This article was adapted from Kameena Ballard's post to the Autism Speaks blog at autismspeaks.org/blog

Puberty and Adolescence Resources

A toolkit presented by the Autism Speaks ATN/AIR-P

Puberty can be a time of mixed feelings for parents and preteens. It can be hard for preteens to understand the many changes that come along with puberty. Also, parents may feel unsure of how to explain these changes to their child. All parents eventually face the challenge of teaching their children about the natural changes of puberty. Parents of preteens with autism spectrum disorder (ASD) may need the help of additional strategies to ease the transition. The aim of this toolkit is to provide guidance on the subject of puberty that can be directly applied to preteens with ASD. These resources are meant to increase families' understanding of puberty and their ability to adapt to these changes confidently.

Topics covered include:

- Body changes
- Self-care and hygiene
- Public vs. private rules and behaviors
- Staying safe: strangers, secrets and touching
- Safety planning for runners and wanderers
- Safety planning for increased aggression
- Internet safety

Available for free download at
CHLA.org/AutismSpeaksKit



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Example: This showering narrative can be used as a visual aid or as a reminder card to encourage good hygiene.

Example Parent Tips: Body Changes

Start early with teaching privacy.

With siblings and therapists often around, privacy is difficult to find, but is absolutely appropriate at a certain point in life. Help your child learn when that is and how to safely obtain it.

Model appropriate hygiene behavior.

Let your child watch you when you shave, put on deodorant or perform any other suitable activity that maintains good hygiene.

Use the correct language for body parts and body functions.

Our children are all going to grow up to be adults one day and need to be taught proper terms for mature subject matter.

Start practicing early.

The sooner you and your child can develop a routine, the sooner he or she will get used to it. Teaching skills early makes it easier to incorporate them into everyday life.

It is important to keep in mind that while youth with ASD often progress in ways that are different from other children, their bodies generally develop at a similar speed as their peers'. Children with ASD may have unique responses to what is happening to their bodies and may need additional guidance when navigating this time of transition.

Research Highlight: Church Health Ambassadors Help Increase Autism Awareness



Navigating the complex health care and health insurance systems can be very difficult for families of children with autism spectrum disorder. Every child with autism has unique needs and concerns and there is no single treatment path. In addition, kids with autism tend to have other related medical conditions such as sleep disorders, seizures, constipation or oral health problems. For these reasons, accessing high-quality assessment services and coordinated care for autism is both more important and more difficult for families. In order for families to be successful, they need to know where to go, whom to talk to and what type of questions to ask in order to get the best care for their children.

However, minority communities, specifically African-American and Latino families, often lack crucial information regarding child development and developmental disorders, and face significant barriers to accessing the care and treatment services that their children need. Many organizations, including Children's Hospital Los Angeles, are working with their communities to develop new education and outreach programs that focus on navigation as an approach to help families learn about autism and other developmental disorders, access developmental assessment and diagnosis services, and then advocate for their children with care providers, insurers and schools. In Los Angeles, we

are working with promotores—community health workers—to help Latino families understand and access autism services.

A similar community-based program has been developed in Wisconsin, which focuses on training local church leaders (mainly the pastor's wife or husband) to become health ambassadors for their communities. These health ambassadors are trained to recognize the signs for autism, dispel myths, and connect parents to the most appropriate services. Marquette University researchers recently evaluated the impact of this program and found that the training improved the health ambassadors' ability to identify behaviors associated with autism, and increased their confidence in referring children for autism screening. This new study was published in the *Journal of Pediatric Nursing*. The church health ambassador program taps into an already trusted resource within the African-American community, and involving church leaders in autism awareness efforts may be an effective strategy to reach this vulnerable population. Health ambassadors could also be expanded to barber shops and hair salons to help improve health outcomes for other conditions and diseases within underserved communities.

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Upcoming Community Events

AMC Sensory-Friendly Films

Kids can enjoy their favorite films in an accepting environment, where the lights are up, the sound is turned down, and they can get up, dance, walk and even shout! Locations throughout L.A. Visit: CHLA.org/AMCSensoryFriendly for more information.

Parent Support Group—Facilitated by CARE, Inc.

Every Monday, 6 – 7:30 p.m.
15315 Magnolia Blvd.
Sherman Oaks, CA 91403
<http://www.careautism.org>

Family Autism Event—Pretend City Children's Museum

The last Monday of each month, 5 – 7:30 p.m.
29 Hubble, Irvine, CA 92618
<http://www.pretendcity.org/>

Special Needs Resource Fair

Sunday, May 15, 2016, 11 a.m. to 3 p.m.
The Help Group
13164 Burbank Blvd.
Sherman Oaks, CA 91401
Free
For further information contact Tracy Peters at tpeters@thehelpgroup.org or 310-751-1486.
CHLA.org/TheHelpGroupFair

Alma Family Services

10th Annual Centro Estrella's Resource Fair
Saturday, June 11, 2016
9:30 a.m. – 1:30 p.m.
4701 Cesar E. Chavez Ave.
Los Angeles, CA 90022
For more information, call Lisette Guzman at 323-981-9714.

Stephanie's Day

Saturday, June 11, 2016, 10 a.m. to 2 p.m.
CBS Studios
4200 Radford Ave.
Studio City, CA 91604
Free admission and parking
For any questions and concerns contact tlgile@cbs.com or 818-655-2022.